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Supreme Court of the United States

October Term, 1980

Nos. 79-1404, 79-1408, 79-1415, 79-1489

PENNHURST STATE SCHOOL AND HOSPITAL, et al.,
Petitioners,

v.

TERRI LEE HALDERMAN, et al.,
PENNSYLVANIA ASSOCIATION FOR RETARDED CITIZENS, et al., and
UNITED STATES OF AMERICA
Respondents.

On Writ of Certiorari To The United States Court of Appeals for the Third Circuit

BRIEF FOR THE CONNECTICUT ASSOCIATION FOR RETARDED CITIZENS, INC. THE STATE OF CONNECTICUT OFFICE OF PROTECTION AND ADVOCACY FOR HANDICAPPED AND DEVELOPMENTALLY DISABLED PERSONS, et al. AMICI CURIAE

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BRIEF FOR THE CONNECTICUT ASSOCIATION FOR RETARDED CITIZENS, INC., THE STATE OF CONNECTICUT OFFICE OF PROTECTION AND ADVOCACY FOR HANDICAPPED AND DEVELOPMENTALLY DISABLED PERSONS, et al. AMICI CURIAE

INTEREST OF THE AMICI

The Attorney General of Connecticut, purporting to represent the interests of this state, argues in his brief that the decision below will interfere with Connecticut's method of caring for its retarded citizens and that it will impose a financial burden on its taxpayers. The Attorney General does not express the views of the disabled citizens of this State and the principal organizations that serve them. *Amici* (whose interests are described more fully below) believe that it is important that the Court understand that the system of care the Attorney General would preserve is little more than a series of large, impersonal and dehumanizing institutions, the long term operation of which is inconsistent with state policy adopted by the Commissioner of Connecticut's Office of Mental Retardation in 1973. *Amici* contend that Connecticut's reliance on outmoded institutions is not only harmful for the persons consigned there, but also promotes the breakdown of family ties, and increases stress on the family unit. *Amici* also contend that the Attorney General's unsupported claim that a community service delivery system for retarded persons is too expensive is simply untrue. *Amici* believe that the decision below must be sustained so that public officials can be required to implement the policy that was adopted by Connecticut in 1973 — that *all* retarded people should live among their fellow human beings rather than in isolated institutions.

1. The Connecticut Association For Retarded Citizens, Inc. [CARC] is a private non-profit corporation created under Connecticut's laws in 1951, has twenty-five member chapters and a membership of 9,100 persons statewide. The purposes of the organization are to promote the general welfare and protect the rights of Connecticut's retarded citizens. Its membership includes parents, other relatives, guardians, and friends of retarded persons and retarded people themselves who live at home or in Connecticut's two large dehumanizing institutions — the Mansfield and Southbury Training Schools. For twenty-nine years CARC and its member chapters have conducted programs for retarded persons and acted as advocates for them. In the face of the exclusion of retarded persons from generic services, these parents joined together, originally, to create and operate community-based services through their association, and then to secure passage of legislation to mandate provision of such services and more recently, to enforce the duties of responsible public agencies to provide community-based educational, residential, vocational, recreational and other opportunities for retarded people so that they can live among rather than separate from their fellow human beings.

2. The State of Connecticut Office of Protection and Advocacy for Handicapped and Developmentally Disabled Persons was established pursuant to 42 U.S.C. § 6012 and Connecticut General Statutes § 46a-10. Its Director of Advocacy, Eliot Dober, was appointed by Governor Ella Grasso and is empowered to act as an advocate for handicapped persons and to initiate and fund legal actions to protect their rights. Mr. Dober has become increasingly concerned about programs of state officials which have resulted in indefinite placement of disabled persons in nursing homes and institutions for which the sole articulated justification is the unavailability of appropriately structured community settings.

3. The Connecticut Coordinating Committee of the Handicapped, Inc. (CCCH) is a statewide, consumer-oriented, private, non-profit corporation created under the laws of Connecticut in 1977. Its principal objective is the achievement of equal opportunity for the state's disabled citizens in all phases of their lives: housing, employment, recreation, transportation, and education. The CCCH is particularly concerned about arbitrary requirements placed on Connecticut's public assistance and service programs for handicapped persons which force such a large percentage of Connecticut's disabled citizens into nursing homes, institutions and similarly inappropriate facilities where their opportunity to participate in and enjoy normal activities is substantially curtailed.

4. The Mental Health Association of Connecticut, Inc. is a private, non-profit corporation founded under the laws of Connecticut in 1908, and has 900 members statewide. The purposes of the Association are to educate the general public on matters of concern to persons with mental disabilities, to protect the rights of mentally handicapped citizens, and to secure passage of laws providing for the development of community services in order to advance its goals of care and treatment in the least restrictive environment. The Association is particularly concerned about the inadequacies in Connecticut's institutions for disabled people and the state's policy of dumping hundreds of residents from state institutions into nursing homes which are unable to respond to the needs of mentally handicapped people.

5. The Connecticut Citizens Concerned with Convalescent Care is a coalition of individuals and agencies concerned with adequate care and the rights of elderly and handicapped persons living in Connecticut's nursing homes. The Coalition was formed in 1979 by the Gray Panthers, the Coalition on Aging, the Area Council on Aging of the State Department on Aging, the Mental Health Association of Connecticut, Connecticut Legal Services, Inc. and the

Connecticut Association for Retarded Citizens, Inc. The purposes of the Coalition are to advocate for individual residents of nursing homes and to secure passage of laws that insure appropriate care and treatment for these residents and protect their rights.

6. The Low Income Planning Agency, Inc., is a private, non-profit corporation established in 1974 to encourage, promote and stimulate the development of community resources with a particular interest in securing human rights established and guaranteed by law regardless of race, color, religion, creed, age, marital status, national origin, sex, mental retardation or physical disability. Governed by a Board of Directors, fifty-one percent of whom are low-income persons from communities throughout Connecticut, the Agency favors deinstitutionalization and the development of community-based services for handicapped persons, believing that these persons, their families, and the community at large benefit from the fullest possible development of the human resources of all of its citizens.

SUMMARY OF ARGUMENT

Connecticut has filed a brief supporting Pennsylvania's position that the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. § 6000 *et seq.* (hereinafter cited as DD Act), does not support judicial orders providing relief to retarded persons subjected to a harmful institutional environment. This responding brief sets forth the views of Connecticut organizations that serve disabled persons and of disabled citizens themselves.

The arguments advanced by the State of Connecticut in its brief are in sharp conflict with the position taken by the State of Connecticut in 1973 in *Project "Challenge", The Long Range Plan of the Office of Mental Retardation* by the Commissioner of Connecticut's Department of Mental Retardation, then, as now, Gareth Thorne:

> There is no simple answer to planning a future for more than 45,000 mentally retarded people in Connecticut; but the courts of the land, and the people who have given great thought to this issue — not only the parents but the professionals as well, have strongly indicated and pressured a course of action which ensures the rights of the mentally handicapped person to live in partnership with his fellow beings. To make any other decision would be to turn away from this central issue and to thereby seek expedient means for avoiding a major social and legal responsibility. One of the greatest temptations that society faces is to treat only the symptoms of the major problems brought about by society's failure in the past to deal properly with the problem of the mentally handicapped. The symptoms that are so frequently dealt with relate to the conditions found in the majority of the institutions in the United States and the temptation to somehow with a few dollars patch these facilities up, or in some instances to rebuild them as continuing warehouses of human beings. The problem basically is that outmoded institutions exist, and every effort must be made to resolve this problem

> and to prevent it from occurring again by literally tearing outmoded facilities down brick by brick until nothing remains, and in this process bring the handicapped person back home to the community where he belongs.[1]

Project "Challenge", The Long Range Plan of the Office of Mental Retardation, 1 (1973).

These views were set out in a 1973 planning document, *Project "Challenge",* that called for the development of small home-like community settings and community support systems to accommodate Connecticut's retarded citizens to make their continued institutionalization unnecessary. Two years later the Congress also reached the conclusion that the consignment of retarded persons to isolated institutions was harmful, and in the Bill of Rights provisions of the DD Act, 42 U.S.C. § 6010, required that it be ended in the same way. It is precisely because Connecticut has not implemented this policy and, in the process, eliminated the tragic warehousing of human beings in this state that the disabled citizens of this state and the organizations that serve them argue below that the Third Circuit Court of Appeals decision in *Halderman* v. *Pennhurst,* 612 F. 2d 84 (3rd Cir. 1979) must be affirmed.[2]

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[1]The Commissioner of Mental Retardation apparently has strong reservations about representations made in Connecticut's brief. In a public statement dated September 22, 1980 marked by the Commissioner for wide distribution he said:

> "I wish to make it perfectly clear that the Commissioner of the Connecticut Department of Mental Retardation did not file a brief nor did he participate in the preparation of the brief by the Attorney General's office."

[2]Two of these organizations, the Connecticut Association for Retarded Citizens and the State of Connecticut Office of Protection and Advocacy for Handicapped and Developmentally Disabled Persons, together with families with retarded members and disabled residents of the Mansfield Training School and equally inappropriate nursing homes have also initiated litigation to end the harmful consignment of retarded persons to those institutions. *See, Connecticut Association for Retarded Citizens v. Gareth Thorne,* No. H78-653 (D. Conn., filed Dec. 6, 1978).

ARGUMENT

1. THE FAILURE OF INSTITUTIONS IN CONNECTICUT

Connecticut's first institution for retarded people was established in 1858 to educate individuals who, because of their handicapping conditions, were unable to effectively use community-based educational facilities.[3] That institution, the Connecticut School for Imbeciles at Lakeville, Connecticut, grew from an educational facility with fifteen students in 1858 to a facility with 304 residents in 1915. Then, in the midst of the eugenics scare, the Connecticut Legislature appropriated $200,000 to expand and consolidate the School for Imbeciles with the Connecticut Colony for Epileptics at a new facility in Mansfield, Connecticut today called the Mansfield Training School. The superintendent of the School for Imbeciles explained the purpose of this expansion as follows:

> Stop the supply of the vicious, the weak, the no-willed people who cannot support themselves in the community — of the criminals and prostitutes and paupers, by cutting off the supply at its source, namely — by

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[3] *Report of the Commissioners on Idiocy*, 17 (1856) (On file at the Connecticut State Library).

On January 4, 1974, the Director of Administrative Services of Connecticut's Office of Mental Retardation, describing the Connecticut Community Residence Program, said:

> The past five years have seen the intensification of a national effort to move retarded individuals from institutions to a variety of community settings. Community placement has become the major mental retardation program in many states. In view of this "new" thrust, it is of interest to note that over 100 years ago — in 1866 — S.G. Howe wrote, "In organizing a new institution there should be built only a building for school rooms, music rooms, and workshops; and these should be in or near the center of a dense population. For other purposes, ordinary houses would suffice."

DuBrow, The Connecticut Community Residence Program (January 4, 1974).

> providing adequate custodial care for the feeble minded of the State. This is especially important in the case of women of child-bearing age. Admission to the Lakeville School has been sought for many of this class during the past year, but there was no room for them. *The Menace of the Feeble-Minded At Large in Connecticut*, 9 (1915) (On file at The Connecticut State Library).

These official efforts to separate retarded persons from society, and the concomitant failure to provide any services for retarded people in the community, led to such rapid growth in the size of the Mansfield facility that by 1934 it housed 1159 inmates and had a waiting list of 1073.[4]

This increased demand for services of some kind, it was thought, necessitated a second institution for retarded persons at Southbury, Connecticut, which opened in 1941. The Southbury Training School was intended to be an educational facility that would train and *return its residents promptly to community settings.* Yale Professor of Psychology, Dr. Seymour Sarason, has described the failure of that stated purpose at Southbury:

> [T]he Southbury Training School was for some time an international showcase because of its striking architectural features, country setting, commitment to being an educational rather than a custodial setting, and its objective of returning its residents as quickly as possible to the community. . . . The educational emphasis was a response to the fact that Southbury had been built to take care of the waiting list of the other and much older training school. Needless to say, things did not work out as they were supposed to, and it was not long before Southbury had its own waiting list and had settled into familiar institutional traditions.

S. Sarason and J. Doris, *Educational Handicap, Public Policy, and Social History*, 85 (1979).

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[4] *Biennial Report of the Mansfield State Training School and Hospital*, (1934) (On file at the Connecticut State Library).

The failure of Southbury Training School led parents and professionals alike to the conclusion that institutions had not responded to either the needs of their residents or to the complex needs of families with handicapped children.

> Far from being possible vehicles for solving problems, these institutions are the problem. They reflect and perpetuate the segregation mentality, the major consequence of which is the erection of barriers between the community and the institution. These institutions are like ghettos; over time those within and without feel comfortable staying apart, colluding, so to speak, in the fiction that this is the best and most "natural" state of affairs. Until, of course, the scandals and exposes destroy the fiction.

S. Sarason and J. Doris, *Educational Handicap, Public Policy, and Social History,* 93 (1979).

The pattern was all too familiar. A family kept its retarded member at home despite enormous pressure without professional guidance as to how to manage and extinguish negative behaviors, without respite care, and without the necessary vocational and other community day programs until the family disintegrated or made the only other available decision (which did little to alleviate the strain on the family) — put its retarded family member in an institution. The stress caused by the necessity of providing constant care for a handicapped child at home was then replaced with the new and often more devastating stress created among family members who felt failure and guilt about permanently placing a family member so far away in a dehumanizing institution.[5]

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[5]Connecticut's Commissioner of Retardation, in a letter dated December 15, 1977 to Mr. Gene Broumas, President's Commission on Mental Health,has accurately expressed the devastating effect institutionalization can have on the retarded person as well:

> Lack of a full array of the services described above had led to an historical situation whereby large numbers of developmentally disabled children have been placed into an institutional environment which has exacerbated their handicap by excluding

2. THE REGIONAL CENTER SYSTEM — AN OPPORTUNITY LOST

In 1959 Governor Abraham Ribicoff, other public officials and parents concluded that families with retarded members could best be helped not by creating another institution or by fixing up the old ones but by setting up a community service network to support families so that they could remain an integral part of the active treatment process and be included as a vital force in the disabled person's life. To this end they agreed to develop twelve regional centers, the primary purpose of which would be to support and assist families and disabled people in the community so as to make institutionalization unnecessary. It was evident to professionals who set up the regional center system in 1960 that indeed institutions were unnecessary:

> We quickly found that individuals on the emergency waiting list were there not because they required institutional care but because a variety of community services and programs (such as group homes, homemaker services, parent education and counseling, baby-sitting help, marital counseling) were not available or, if available, were unknown to the family. Some of these families were requesting institutionalization because they had been told that it was the best course of action, and not because they personally desired it. There was not a single case, regardless of severity, for which an alternative to institutionalization was not possible, if community resources, actual and potential, could be utilized. . . . What struck us forcefully was that these alternatives would *create* fewer major social problems than institutionalization would (or has). Indeed, in the

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emotional spontaneity and individual attention and love from their lives. As a result, there are few institutionalized mentally retarded persons who do not have at least some degree of emotional disturbance which become an additional barrier to their reaching their potential.

> process of developing some of these alternatives we found many people in the community grateful for the opportunity to be helpful, to be part of something that brought new knowledge and challenge into their lives...
> . . . .
>
> These were exciting months for everyone . . . . If the millions that were going into buildings were made available to us we could develop scores of programs and settings in and by the community, and in many ways would bring new meaning into the lives of many people.

S. Sarason and J. Doris, *Educational Handicap, Public Policy, and Social History,* 87, 88 (1979).

As a result of the Kennedy initatives[6] and the several acts of Congress[7] during the 1960's, Connecticut extended its regional center system throughout the state. Administrative offices with professional staff opened in each of the twelve regions to assist families and develop and coordinate services. Legislation was enacted authorizing state grants to

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[6]In 1963 President John F. Kennedy asked the Congress to enact legislation:

> To retain in and return to the community the . . . mentally retarded, and there to restore and revitalize their lives through better health programs and strengthened educational and rehabilitation services; and
>
> To reinforce the will and capacity of our communities to meet these problems in order that the communities, in turn, can reinforce the will and capacity of the individual and individual families.

109 *Cong. Rec.* 1842 (1963).

[7]*See,* The Maternal and Child Health and Mental Retardation Planning Amendments of 1963, P.L. 88-156, 77 Stat. 273 (1963); The Mental Retardation Facilities and Community Mental Health Center Construction Act of 1963, P.L. 88-164, 77 Stat. 282 (1963); The Mental Retardation Facilities and Community Mental Health Centers Construction Act Amendments of 1965, P.L. 89-105, 79 Stat. 427 (1965); and The Developmental Disabilities Services and Facilities Construction Act of 1970, P.L. 91-517, 84 Stat. 1316, § 207 (1970).

private non-profit agencies providing day care, recreation, vocational training and sheltered workshop programs.[8] These developments culminated in 1973 with the adoption of the policy set out in the State's long range plan[9] that *all* retarded people should live among their fellow human beings rather than in isolated institutions.[10]

During this period Connecticut used federal funds under the Title XIX program[11] to develop community residential alternatives to accommodate some of the over 1000 retarded persons who were scheduled to be returned to the community from institutions. Governor Meskill announced that 100 group homes would be developed within two years, and, in fact, twenty-two were developed by 1975.

By the mid-1970's, after fifteen years of progress, Connecticut had in place a system which provided it with a unique opportunity to displace its institutions. Unfortunately, Connecticut in 1980 still has not acted on that opportunity. For example, aside from the development of a few apartments and foster homes, only three group homes

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[8]That legislation, originally codified as Connecticut General Statutes §§ 19-4d, 19-4e, and 19-4f, is now found at Connecticut General Statutes §§ 19-571, 19-572, and 19-573.

[9]The policy, found in the preamble of Connecticut's 1973 long range plan, is set out at page 5, *supra*.

[10]In 1974 the Director of Administrative Services of the Connecticut Office of Mental Retardation described the rationale behind its policy of returning retarded people to community settings as follows:

> Policy regarding the development and use of community residential programs for the retarded is based on the belief that for many, *regardless of the level of retardation,* a place to live in a community setting is essential to their growth and well-being as persons and citizens.

DuBrow, The Connecticut Community Residence Program, (January 4, 1974).

[11]The regulations implementing the 1971 amendments to Title XIX covering funding of two categories of intermediate care facilities for the mentally retarded are now codified at 42 C.F.R. Part 442.

have been opened by the state since 1975, and one has closed.

Connecticut soon identified another and more expedient method of reducing the size of its institutions. Contrary to the will of Congress[12] Connecticut began literally "dumping" hundreds of retarded persons into nursing homes[13] with patient populations as high as 500, and using then, as now, the excuse that overcrowding and deplorable

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[12]In 1971, Senator Bellmon, presenting an amendment to Title XIX to end inappropriate and expensive nursing home transfers like those subsequently undertaken by Connecticut, stated:

> Intermediate care was established because many thousands of assistance recipients were being classified as skilled nursing home patients even though they needed a lower level of care. That was done because federal matching funds were available for skilled nursing care but was not available for institutional care below that level. 117 *Cong. Rec.* 44720 (1971).

[13]Connecticut's Deputy Commissioner of the Department of Mental Retardation, in testimony before the State of Connecticut Commission on Hospitals and Health Care on August 2, 1979, stated:

> There have been in the past people who are profoundly or severely retarded who needed care but probably not quite the medical care or nursing care the SNF [Skilled Nursing Facility] requires or SNF provides.
>
> . . . .
>
> There are not enough of the appropriate number of beds for mentally retarded people in the state to provide safe and humane accommodations for them and until that exists we're going to have to continue to use skilled housing facilities in the community and to continue to overcrowd our existing facilities.

Connecticut's long range plan itself also supports this view:

> At the present time the Department of Mental Retardation has 736 clients placed in Skilled Nursing Facilities (SNF) in Connecticut. . . .
>
> At this printing, the evaluation has been completed on nearly 40% of the total SNF placements, and based on this sample it is estimated that approximately 300 individuals could be more appropriately served in another type facility. . . .

Project Challenge, 31 (1979)

conditions at the institutions justified large-scale transfers.[14] These transfers were a financial boon to the nursing home industry which, until then, had difficulty filling its facilities and resulted in a significant cost savings for the Department of Mental Retardation and for the State of Connecticut.[15]

Connecticut was apparently well aware that nursing homes were staffed to meet only medical needs of a very

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[14]The Commissioner of Mental Retardation of this state has characterized these occurrences as follows:

> Now, beginning the early seventies, because of staffing problems, because of inadequacy of buildings, three-story buildings at Mansfield, structures at Southbury that needed renovation, overcrowded, superintendents assessed the situation and recognized that the people in their facilities were not getting the 24-hour nursing care at the level that they felt was appropriate to the individual's needs and so, in order to reduce the overcrowding, in order to abandon some outmoded buildings and in order to enable renovations to take place and give the time for new construction of new regional facilities and so forth to occur, movements were made of those people that we felt were at risk in our situation to skilled nursing facilities where we felt they would be — receive more appropriate care than we could offer, recognizing it was institutional care and we never in any way described that as being [de] institutionalization, it was a lateral institutional move, and the plan being that — it was and still is. . . .
>
> That's still part of the process, so we're working with a backlog of a large — a waiting list, overcrowded institutional facilities, lack of other alternatives, we have been working at that certainly ever since I have been here . . .

Deposition of Gareth Thorne, taken on February 7, 1980 in *Dober* v. *Thorne,* No. H79-498, 40, 41 (D. Conn. filed August 31, 1979).

[15]Page 31 of the official planning document, *Project Challenge,* (1979) indicates that financial responsibility for persons transferred from state institutions into nursing homes rests with another state agency:

> These clients [those in SNF facilities] continue to be the responsibility of the Department, although the cost of their care is paid for by Title XIX through the Department of Income Maintenance.

limited (elderly and infirm) population.[16] Even so Connecticut chose to transfer retarded people whose primary needs are for educational and habilitative services. This wholesale "dumping" of retarded persons into facilities incapable of meeting their needs resulted in a tragic chapter in the care of Connecticut's handicapped citizens.[17] Current

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[16]The Health Systems Agency of North Central Connecticut at page 2 of its panel report of April 15, 1977 regarding the *Lorraine Manor Proposal to Convert Facility to Habilitative Nursing Facility* states:

> Ms. Toni Richardson, Director of the Division of Licensing of the Department of Mental Retardation, indicated that the license which would be awarded to Lorraine Manor would be for the severely and profoundly retarded patient with multiple handicaps who also has intense medical needs. Approximately 40 people have been identified in Connecticut who fall into this category. . . .

[17]Frequently the staff at such facilities are not familiar with and therefore cannot identify and respond to the developmental needs of retarded people. On January 16, 1979 the Director of the Division of Survey and Certification Operations of the United States Department of Health, Education and Welfare in a letter to the Connecticut Department of Health Services described the failure of two Hartford-area skilled nursing facilities to recognize and meet the developmental needs of their 200 retarded residents:

> During the brief time that I was in each of the facilities programmatic activities were at an absolute minimum. A feeding program was in process at Hillside Manor for three or four residents. It appeared that many more of the residents required similar training. Other program activities could not be observed because of the time of day I was in each facility. However, available staff did not appear to be adequate to provide any kind of ongoing program direction to improve the functioning levels of the residents. Furthermore, many residents were observed slouched down in wheelchairs and curled up in fetal positions throughout each facility. Staff did not appear to be aware of the importance of proper positioning to avoid the development and further aggravation of contractures.
>
> My observation based on a very limited walk through both of the facilities was consistent with the findings of the federal survey team which visited them early in the Fall.

state planning documents, however, contain no concrete plans to relocate this class of reinstitutionalized people to appropriate community living arrangements.

In 1975 in Section 6010 of the Developmentally Disabled Assistance and Bill of Rights Act, the Congress studied and addressed the chronic and continuing deficiencies that plagued the nation's institutions for retarded persons. The Chairman of the Senate Labor and Public Welfare Committee, during floor debate in the Senate, echoed the findings and concerns expressed by Connecticut's public officials in its 1973 long range plan:[18]

> Over the past few years, the horrifying conditions which exist in most of the public residential institutions for the mentally retarded . . . have provided shocking testimony to the inhuman way we care for such persons. The conditions at Willowbrook, at Partlow in Alabama, and at Rosewood in Maryland, and at many other institutions have shown beyond a shadow of a doubt that the treatment of these individuals is worse than all of us would like to admit.
>
> Steps to scale down many of these large custodial institutions have resulted in not-so-large institutions, often with not much improved care and with little follow-up. This has been true at Willowbrook: in 1965 and again in 1972, broad criticism has been levied at this institution; all indications point toward little change, unless substantial legal advocacy pressure is forthcoming. While much can be said about the lack of available funds to improve conditions at these institutions at some point this country must draw the line.

121 *Cong. Rec.* 16516-17 (1975).

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[18] *Compare* Statement taken from the 1973 Connecticut long range plan at page 5 *supra*.

The Congress concluded, just as had Connecticut officials two years earlier, that the problems presented by the existence of large-scale, isolated institutions could be remedied only by phasing them out and returning retarded people to communities among their fellow human beings.[19]

Connecticut argues that it does not want to be required to implement a public policy that requires it to provide minimally adequate habilitation in the least separate, most integrated community settings. Seven years have passed since the state itself formally adopted that very policy in its long range plan. Yet, community development remains at a standstill and families with handicapped members continue to disintegrate in the absence of community services until, in desperation, they request the only help available — a residential placement in a state institution.[20] Meanwhile, the residents at the Mansfield and Southbury Training Schools regress and deteriorate in the absence of an effective

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[19]These findings of the Congress are:

> It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in these institutions at all. Efforts to assure proper treatment, education, and habilitation services in large institutions should not deflect attention from the fact that most of these institutions themselves are anachronisms, and that rapid steps should be taken to phase them out. Many of these institutions by their very nature, their size, their isolation, their impersonality, are unsuitable for treatment, education, and habilitation programs.

S Rep. 94-160, 94th Cong., 1st Sess. (1975) at 32, 33

[20]The urgent waiting list for a residential placement in this state now contains some three hundred names. An urgent case is defined at page 28 of the 1979 revision of *Project Challenge* as one where a residential placement is necessary to prevent major deterioration or dysfunctioning of the client or his family unit.

program[21] and suffer under inhumane conditions similar to

[21]On March 15, 1976 the President of *amicus curiae*, the Mansfield Parents Association, in a letter to Governor Ella Grasso, wrote:

> The lack of appropriations for personnel for the new cottages is not the only problem of "direct care" employee shortage. There has always been extreme "direct care" staff shortages throughout the institutional complex, including the hospital units.

Despite the expenditure of millions of federal Title XIX dollars ostensibly to meet minimum federal program standards, the Medicaid survey team which, in Connecticut, is housed within the Department of Mental Retardation, found in its survey report dated September 6, 1979 that the absence of program, especially among Mansfield Training School's most severely handicapped residents, is so pronounced that residents are literally warehoused:

> there is no time for the aides to spend in the development of clients' self-help skills. . . .
>
> . . . .
>
> All the multiple handicapped and non-ambulatory residents do not currently have planned daily activity and exercise periods nor have the clients been rendered mobile by methods or devices such as walkers, canes, etc. . . . .
>
> . . . .
>
> Every resident who does not eliminate appropriately and independently is not included in a toilet training program.
>
> . . . .
>
> Although clients who were incontinent were changed, they were changed on the bare floor with little consideration for privacy, comfort and sanitation.
>
> . . . .
>
> The clients are receiving only basic care with little programming to foster their development.

The Medicaid Survey Team also found during nine successive inspection tours of the best facilities at Mansfield Training School during the period October 18, 1978 through October 23, 1979 that professionals spend their time on paperwork rather than with clients, that direct care staff are inadequately trained to implement programs especially for the severely and profoundly retarded and that even those few clients that have written habilitation plans are not receiving the needed services.

The program at Southbury Training School is no better. At page 5 of the Annual Report for that facility for the period 1978-79, its superintendent said:

> "[L]iterally hundreds of Southbury residents have been penalized by admission since it is not possible to provide programs to meet their needs, especially those over 21 years of age."

those found at Pennhurst — conditions that cannot be tolerated in a free society.[22]

[22]On March 15, 1976, the President of *amicus curiae* Mansfield Parents Association, wrote about conditions at the Mansfield facility in a letter to Governor Ella Grasso:

> The Mansfield parents have a vested interest in the Training School and are duty bound and obligated to inform you of the unsafe and unhealthy conditions that continue to plague the institution because our bi-partisan political structure fails to care about their unfortunate and unproductive constituents.

Three years later the employees' union representatives from Mansfield Training School, in testimony before the Appropriations Committee of the Connecticut Legislature on February 27, 1979, indicated that essentially the same conditions still existed:

> Ms. Dubrino: Oh, the turnover rate at Mansfield is about 50% per year. We see people come in and work for one or two months and be totally discouraged with conditions that they leave and this does not provide a good continuity of services on the ward.

The inadequacies of Mansfield and its separation from the normal checks and balances of society have resulted in substantial and often unexplained casualties among residents. In each month during the period January, 1979 - April, 1979 at least twenty percent of the residents suffered injuries. In April of 1979, for example, 243 residents sustained 345 injuries including nine severe injuries — those resulting in fracture, hospitalization or death.

Similar longstanding problems plague the Southbury Training School. Since November of 1978, Connecticut's Medicaid Survey Team has found repeated widespread and improper use of chemical and physical restraints. The United States Department of Health and Human Services in a letter to Commissioner Thorne dated August 21, 1980, has expressed its deep concern over these problems:

> A recent review by the DMR's IPR/UR findings as well as the DMR's surveyor findings by personnel in my office indicated a long history of deficiencies in the areas of restraints, plans of care and medication review.
>
> . . . .
>
> The physical and psychological functioning of clients appeared impaired by the ongoing use of physical restraints . . . . the use of restraints, according to the team, in some instances, constitutes a health threatening practice for the client involved.
>
> . . . .
>
> This intervention, it appears, is little more than a "carte blanche" opportunity to utilize restraints as a substitute for activities and/or treatments.

The Third Circuit Court of Appeals decision in *Halderman* v. *Pennhurst* must be affirmed so that Connecticut can be held to the policy it articulated seven years ago, and so that the deplorable conditions at Connecticut's institutions can be remedied precisely as the Congress and officials of this state have concluded is necessary.

3. COMMUNITY LIVING IS NOT MORE COSTLY THAN INSTITUTIONALIZATION

Connecticut's *amicus* brief argues that placing retarded persons in properly structured community living arrangements will be more costly than keeping them in institutions. Thus, it argues, that implementation of the Third Circuit Court of Appeals decision constitutes significant federal interference into state affairs in violation of the Tenth Amendment to the United States Constitution. In particular, at page four of its brief, it asserts that:

> The Department's most recent calculations, however indicate that new construction costs an average of $37,322.42 per client bed, while purchased renovated group homes cost an average of $26,399.29 per client bed. Given the rapidly rising costs of moving a significant number of the three thousand (3,000) Connecticut citizens in the campus programs to community living arrangements would be well in excess of ninety million dollars (90,000,000.00).

Even if these cost figures are accepted, one does not have to look beyond Connecticut's own long range plan to see that the conclusion it would have this Court reach is inaccurate. *Project Challenge* lists as community-based alternatives to institutions: foster homes (community training homes), apartment living and group homes, none of which have to include capital outlay. Of the community beds now in place in this state, none involved new construction, and only a

small fraction were purchased and renovated.[23] Also, in addition to the foster care, apartment rental and leasing options set out in *Project Challenge*, community alternatives can be developed by contracting with private, non-profit or proprietary service providers. Again, all options involve no capital cost and are commonly used in other states. Such costs may also be covered by subsidies from the United States Department of Housing and Urban Development.

In support of its second argument that implementation of the Bill of Rights provisions of the DD Act as interpreted by the Third Circuit Court of Appeals will be costly, Connecticut argues that:

> [S]ignificant increases in annual operating costs will accrue due to the necessity of providing increased direct care staff and medical and psychological support services over a geographically diverse area.

Once again, we believe this assertion is misleading both because institutional care in this state is becoming extremely expensive[24] and because it ignores mounting evidence that community alternatives to institutional care are less costly.

Dr. Ronald Conley, expert witness for the plaintiffs in *Halderman v. Pennhurst* on the economics of services to mentally retarded people, argued as long ago as 1973 that small home-like community facilities for retarded people were cheaper than large isolated institutions. In support of this assertion he argued:

> (1) Because small facilities can be located in communities, it should be possible for them to obtain many services at a cost lower than would be incurred if the

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[23] *Project Challenge*, 12, 15-19 (1979)

[24] DMR has estimated in materials recently submitted to the Connecticut Commission on Hospitals and Health Care that annual institutional operating costs will exceed $60,000 for some residents by 1982. *Commission on Hospitals and Health Care Decision*, No. 79-545-S, 4 (1979).

> grams utilizing all community resources related to treatment or habilitation of such individuals to provide comprehensive services in the home community. *Id.* at 16520.

And Representative Tim Carter made clear that:

> We, as a committee, are well aware that treatment of the developmental (sic) disabled should be conducted in that person's community without unnecessarily institutionalizing him. *Id.* at 9976.

Undoubtedly Congress acted with premeditated consistency when it created the Bill of Rights and enacted it in conjunction with other funding and enforcement provisions. All were placed within one Act because all were seen as necessary for reforming those institutions which remained temporarily and for providing individualized "appropriate treatment" to all developmentally disabled persons regardless of treatment setting. Congress' "preference" for deinstitutionalization is pervasive throughout the Act, and clearly apparent in all significant parts. This "preference" ranges in its effect from that of mandatory right (§§ 6010(1) and (2)), to financially related conditions (§ 6010(3) and § 6011), planning requirement (§ 6063(b)), and general aspiration (§ 6000). Certainly the "preference" for deinstitutionalization was not intended to give participating states the unfettered right to continue the shameful overuse of substandard institutions.

C. *A Contrary Interpretation Would Create Absurd Results and Imply Futile Measures Enacted by Congress.*

The Act was the result of the failure and ineffectiveness of earlier funding statutes in eliminating the horrors of mental retardation institutions. It would be a cruel hoax to suggest that despite the addition of personal rights (§§ 6010(1) and (2)), funding conditions

(§§ 6010(3), 6011), planning requirements (§ 6063(b)), and advocacy mechanisms (§ 6012), Congress was once again enacting a mere funding statute. Congress did, in fact, explicitly call it a "Bill of Rights" Act, and rights were to be guaranteed. With respect to the 1978 Amendments, Senator Kennedy stated:

> Everyone in here knows that the only way that change is going to be brought about is the long, difficult, persistent, and dedicated advocacy of those who are prepared to follow through administrative hearings, through hearings on regulations, through challenges in the courts, for the kinds of rights which are being guaranteed in this legislation. That is the way it is done. [124 Cong. Rec. S15663 (daily ed. Sept. 21, 1978).]

Congress passed the Act not with the thought that the states would simply use federal dollars as they had done under past legislation, but with the requirement that specified rights would cease to be violated.

In order to conclude that the rights to treatment and treatment in the least restrictive setting (42 U.S.C. § 6010(1) and (2)) are not mandatory, one would have to believe that in 1978 Congress enacted the following portion of § 6010 as a totally meaningless provision: "The rights . . . described in findings made in this section are in addition to any constitutional or other rights otherwise afforded to all persons." It would be absurd for Congress to *state* that it had enacted viable rights in this section if it had in fact not done so. Such an interpretation would endorse an internal inconsistency in the section that would render implementation of the treatment "rights" an impossibility.

Furthermore, it would be nonsensical to presume that protection of rights under § 6010 was really only intended to cover specific programs actually receiving federal funds. Not only would such an interpretation clash

with the legislative history discussed in the previous section, but it would also mean that states which could not meet the requirements of the state plan would have no obligation to protect the fundamental rights Congress was addressing in the Bill of Rights. Only those states which met the conditions for approval of the plan would have to protect those rights. Thus the most recalcitrant states would be least bound to observe those core rights that on their face apply directly in favor of "persons with developmental disabilities," without restriction.

Even if one were to assume that such an illogical construction were correct, Pennsylvania would still be in violation of § 6063(b)(5)(C), a provision in the 1978 Amendments which makes the protection of rights under § 6010 a condition precedent to the receipt of funds under Title III for all "programs assisted under this chapter." That conclusion is compelled by the fact that Pennsylvania uses much of its federal funds under the Act to provide planning, public awareness and human rights projects which assist every program in the state's developmental disabilities system.

With regard to the use of federal funds it is also well settled by this Court that Congress "does have the power to fix the terms upon which its money allotments to states shall be disbursed." *Oklahoma* v. *Civil Service Commission* 330 U.S. 127, 143 (1947). In that case the Court ruled that state compliance with the Hatch Act was a permissible condition to the right to receive federal highway funds. Thus the Court upheld the removal from office of a member of the State Highway Commission found to have violated the Hatch Act. Surely the same result should attend the less onerous condition Pennsylvania has agreed to in this instance. Any other holding would collapse the entire structure and thrust of the Developmental Disabilities Act.

II. The Act May Be Enforced Under 42 U.S.C. § 1983.

In June, 1980, this Court ruled that individuals who have been deprived of "any rights, privileges, or immunities" provided for under a federal statute are entitled to bring a section 1983 cause of action, *Maine* v. *Thiboutot*, —— U.S. ——, 48 U.S.L.W. 4859, 4860 (June 25, 1980). The Court's decision, which arose under the Social Security Act, was broad enough to encompass the Developmental Disabilities Act. As this Court emphasized, "even were the language ambiguous . . . any doubt as to its meaning, has been resolved by our several cases suggesting, explicitly or implicitly, that the § 1983 remedy broadly encompasses violations of federal statutory as well as constitutional law." (*Id.* at 4860). It is noteworthy that in his dissent Justice Powell observed that the majority's decision would include a wide range of federal statutes. In an appendix he specifically lists the Developmental Disabilities Act (*Id.* at 4869, Part C, par. 12).

Only a couple of weeks before this Court decided *Maine* v. *Thiboutot*, the Southern District Court in West Virginia ruled that § 1983 could be used to enforce rights under a number of statutes which protect mentally retarded individuals including the Developmental Disabilties Act. *Medley* v. *Ginsberg*, No. 78-2099 CH (S.D. W.Va. June 10, 1980).

As has been shown above, both the terms and structure of the Act and its legislative history clearly demonstrate that the Act confers numerous "rights" upon developmentally disabled persons. These include the rights to appropriate treatment and habilitation (§ 6010 (1)) and to treatment in the least restrictive setting (§ 6010(2)). The Act also places specific conditions on the use of Act monies (§ 6010(3), institutional standards; § 6011, habilitation plans; and § 6063, state plan requirements), all of which are designed to cause direct benefits to run in favor of the developmentally disabled.

States wishing to participate in the program freely take on the general duty to provide treatment in the least restrictive setting, as well as the duty to comply with specific grant conditions once funds are received.

These rights are without question "of an essentially personal nature, touching such intimate things as living and eating conditions, freedom from the marks of modern peonage, work at starvation wage levels in degrading poverty." *See Gomez* v. *Florida State Employment Service*, 417 F.2d 569, 579 (5th Cir. 1969). While not labeled "civil" in the Act itself, these rights are intended to eliminate the discrimination against the mentally retarded that was typified by the institutional abuses noted by Congress. They are to be invoked by the mentally retarded themselves where they suffer direct personal harm.

Nothing in the history of § 1983 nor in its interpretation in *Maine* v. *Thiboutot*, *supra*, suggests that human rights, such as the right to treatment, should be less enforceable than statutory rights to money benefits. Indeed, a cause of action under § 1983 is a particularly appropriate means of enforcing these rights since it was realized by Congress that it was the action (or inaction) of state officials that resulted in the abuses mentally retarded people have suffered in the past. Such a cause of action could not unfairly intrude upon state activities since state activities concerning the developmentally disabled were the precise object of the Act as a whole.

Certainly no state that freely and intelligently entered into the cooperative program created by the Act could claim to be surprised to find that Congress wrote enforceable rights into its structure. The language of the Act and the legislative history are plain enough. Likewise, no state can offer objection to a private right of action under § 1983 since Congress was entirely open

when it stated that the right to appropriate treatment "should be protected and assured by the Congress and the courts." H.R. Conf. Rep. 94-473, 42 (1975), [1975] U.S. Code Cong. & Ad. News 943, 961.

A major component of the statutory scheme, of course, is the "protection and advocacy" system created by 42 U.S.C. § 6012, which Congress specifically stipulated must be able to pursue "legal, administrative, and other appropriate remedies" to protect the rights of the developmentally disabled. § 6012(a)(2)(A). A right of action under § 1983 is entirely consonant with the intent of Congress and would do no violence to the statutory program. *Cf. Chapman* v. *Houston Welfare Rights Organization*, 441 U.S. 600, 645, 672 (1979).

As the Court has so recently ruled in *Maine* v. *Thiboutot*, *supra*, the phrase "and laws" within § 1983 permits claims to be brought on violations of rights arising directly under federal statute. The federal Developmentally Disabled Assistance and Bill of Rights Act contains rights the deprivation of which must give rise to exactly this private cause of action.

CONCLUSION

For the reasons set forth above, the American Bar Association urges this Court to affirm the judgment and decree of the Court of Appeals.

Respectfully submitted,

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APPENDIX A

ABA House of Delegates—Policies Adopted August, 1978

COMMENDATION OF REPORT OF PRESIDENT'S COMMISSION ON MENTAL HEALTH

BE IT RESOLVED that the American Bar Association commends the Report of the President's Commission on Mental Health as an important and valuable study for consideration by officials and citizens concerned with improvement of the nation's mental health system; and

BE IT FURTHER RESOLVED that the American Bar Association endorses those recommendations of the President's Commission on Mental Health providing for protection of the human and legal rights of mentally disabled, i.e., the recommendations within the Report's section on "Protecting Basic Rights" which recommend that:

(1) All Federal agencies enforce existing laws and regulations which prohibit discrimination against mentally disabled persons and seek to equalize opportunities for such individuals.

(2) All Federal agencies review their statutes, regulations, and programs for instances of discrimination against mentally handicapped persons.

(3) The Department of Health, Education and Welfare vigorously implement the requirements of the Education for All Handicapped Children Act and formulate regulations to assist school districts to provide for the mental health needs of children and youth.

(4) Each state review its mental health laws and revise them, if necessary to ensure that they provide for:

a) a right to treatment/right to habilitation and to protection from harm for involuntarily confined mental patients and developmentally disabled individuals;

b) a right to treatment in the least restrictive setting;

c) a right to refuse treatment, with careful attention to the circumstances and procedures under which the right may be qualified; and

d) a right to due process when community placement is being considered.

(5) Each state have a "Bill of Rights" for all mentally disabled persons, wherever they reside.

(6) Mentally disabled persons in detention or correctional institutions should have access to appropriate mental health services on a voluntary basis and such access should not be connected with release considerations.

(7) All recipients of Federal funds to provide mental health services be required to adhere to certain basic principles of confidentiality, and that other institutions and facilities be encouraged to follow this practice.

(8) The establishment of advocacy systems for the representation of mentally disabled individuals. In adversary or judicial settings we recognize the importance of counsel to represent not only the mentally disabled client (or those acting in his or her behalf) but also the state or provider against which a claim is made.

(9) Each State review its civil commitment and guardianship laws and revise them, if necessary, to incorporate increased procedural protections.

APPENDIX B

ABA House of Delegates—Policy Adopted August, 1977

IMPLEMENTATION OF FEDERAL RIGHTS FOR THE MENTALLY HANDICAPPED

BE IT RESOLVED that the American Bar Association urges the swift and effective implementation of federal laws and regulations codifying the rights of mentally handicapped persons, and further urges state governments to consider legislation insuring such rights within their respective jurisdictions.